

The Rhetoric and Practice of Partnership: Experiences in the Context of Disability

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ABSTRACT

In this paper we look at the use of “partnership” in the context of disability policy. The contested nature of “partnership” will be examined with reference to *Making a World of Difference Whakanui Oranga*, the New Zealand Disability Strategy (NZDS), and to *Special Education 2000 (SE2000)*. We describe an evaluation study of SE2000, and our experiences of being on the NZDS sector reference group. We look at the difficulties that arise when the tensions between partnership as “means” and partnership as “outcome” are not made clear. We argue that there needs to be closer attention to the relationships between values, research and policy: we argue that relationships have to be valued, that the lives of disabled people have to be valued, and central to the development of disability policy.

Introduction

“Partnership” is used in various contexts in the policy environment in Aotearoa/ New Zealand. These include the:

- Treaty of Waitangi principle of partnership,
- need for consultation with the NZ community as a process on all legislative and policy changes, reviews and implementation,
- need to directly engage with specific communities on issues with specific impact on their lives
- shared decision-making occurring at a practice level between government agencies and individuals or families.

Government and its agencies have used the rhetoric of partnership to engage with many communities, and much progress has been made. However there is a perception in many communities that government is “doing partnership” with a view of partnership as a grudging obligation, that although partnership may not compromise the desired outcome, it does not add value to the outcome, except in terms of broadening ownership of the outcome, and (with perhaps the exception of Treaty partnership) not an outcome in itself, a “tick the partnership box” approach to doing partnership. There is a real reluctance to share power.

Romer et al (2002) argue “The making of disability policy is particularly complex because it incorporates social views, knowledge as well as misconceptions about how people become disabled, and the issue of societal responsibility for their well-being” (p.14). An example is whether disability is viewed as an individual, private trouble, or a matter of public policy. Is disability the responsibility of the individual and their family? Something to be ashamed of and moved out of the public view? Is disability more properly dealt with by professionals who are experts in their field? Is disability a resource issue?

Rosenau (2002) describes the relationship between values, research and policy:

The cultural assumption that disability is a negative experience that has pervaded research literature is a reflection of widely held views in the broader public, views that affect researchers as well as research. Disability activists ask that we focus on these images and their influence. ...The danger of an incomplete or misunderstood picture is that policy will be made on the distorted view (pp.6-7).

Views of partnership and views of disability are inextricably linked, even if rarely explicitly examined. In this paper we attempt to look at the interplay between these views.

Meanings of “partnership”: The Ministry’s uses of “partnership” in publications about SE2000

The publications on the introduction, implementation, and refinement of SE2000 show that “partnership” has been used in two ways. “Partnership” has been constructed both as a *means* or *process* by which successful educational outcomes can be achieved, and as an *outcome* in its own right. Schools should be developing effective partnerships with parents, caregivers and whānau: such partnerships are the essential means by which to deliver good education to children with special needs. Timperley and Robinson (2002, pp.11) have also looked at what they term the two “rationales” of partnership. The first rationale is to further a policy agenda of increased social democracy. The second rationale is more functional – increasing partnership will increase student achievement. They argue that it is necessary to distinguish between these rationales, because:

... the rationales become the criteria against which their respective adherents evaluate the processes and outcomes of partnership.

In the writing about partnership and the implementation of Special Education 2000, more often than not these two meanings are conflated, as the following excerpts show.

In the February 1998 newsletter *Special Education 2000* there were a number of references to the school-parent relationship, and parents rights to be involved in a number of decisions. On the front page under the headline “What’s Happening in Term One” a number of bullet points are listed, including

- Principals and boards of trustees, in consultation with parents/caregivers, decide allocation of Special Education Grant
- Principals, teachers, parent/caregivers and fundholders decide allocation of funding for Ongoing Resourcing Scheme students for Term 2

In a front-page sidebar titled “Letter to Parents/Caregivers” readers were told that

Special Education 2000 is about providing substantially more funding for children with special education needs. This nation-wide programme is to make sure all these children have access to better learning opportunities, wherever they may be.

For this to happen, *Special Education 2000* depends on schools working with parents and caregivers to decide how the special education funds are to be spent to meet the needs of individual children. Your child may be eligible for direct funding through the Ongoing Resourcing Scheme. If not, there are four other initiatives in *Special Education 2000*, including the Special Education Grant, that will provide learning opportunities for your child. There may also be special education teachers in your area who can help. Contact your school and work with them to see how your child will benefit from the new funding.

The provision and use of either individually targeted funding (Ongoing Resourcing scheme – ORS) or bulk funding (the Special Education Grant – SEG) were signalled as areas where parents could expect to participate with schools in decision-making. Inside the document under the heading “4. Special Education Grant” readers are again told that

Schools will need to work with parents/caregivers on how this fund should be spent to meet the needs of individuals and groups of students with moderate to high special needs.

A further sidebar is titled “Schools and Parents/Caregivers – The Key Relationship.” This material also emphasises shared decision-making for allocating funding for both the Ongoing Resourcing Scheme (ORS) and the Special Education Grant (SEG):

A fundamental principle behind *Special Education 2000* is that schools and parents/caregivers together are best placed to decide how the special education needs of individual students should be met. Achieving this depends on close constructive relationships to overcome barriers to students’ learning.

During Term 1 decisions for allocating funding for Ongoing Resource Scheme students should be made by schools, parents/caregivers and fundholders working together. This may be during a regular IEP or special meeting. Schools should consider encouraging parents/caregivers to bring a friend or advocate if they feel they would like support.

Schools should also involve parents/caregivers in the allocation of the Special Education Grant. Funding is now provided to schools rather than centrally because it is believed that schools and parents/caregivers are best able to make resourcing decisions about their students. Such decisions are more likely to be understood and supported if carried out with full consultation.

The last section of the publication is called “Questions and Answers” setting out 10 possible queries. The question/answer relevant to this chapter is:

What do parents do if they feel their child is not being fairly resourced from the Special Education Grant?

The Special Education Grant is provided to schools so they can help students with moderate to high special education needs (not resourced through other *Special Education 2000* initiatives). Boards of trustees have a responsibility to ensure that the grant is used for this purpose. The Education Review Office will review how schools use the Special Education Grant as part of its regular programme.

Parents may wish to discuss with the school how this grant is being used to meet their child’s needs. Any questions should be discussed with the principal and the board of trustees. If necessary the local Ministry of Education Management Centre could then be contacted.

From its earliest dissemination, *Special Education 2000* set clear expectations that parents/caregivers could and should be involved in consultation and decision-making about the allocation of both ORS and SEG funds. With ORS, these decisions might take place as part of the IEP. Boards of trustees could expect to be held accountable by parents and by ERO for the appropriate use of SEG in particular.

Considering partnership as an outcome, Timperely and Robinson (2002) review literature that shows that

... partnership is employed to advance a political and social policy agenda of enhancing democratic participation and responsiveness. Partnership is seen as a new form of governance which provides an alternative to marketisation or paternalistic bureaucracies by bringing together a range of providers and interest groups to tackle intransigent issues (p.10).

The providers and interest groups in SE2000 are schools and parents respectively. The intransigent issue being tackled is the use of limited financial resources to meet the learning needs of students with disabilities.

The *Update for Schools Issue 9* (October 1999), and *Update for Families Issue 3* (October 1999), included a brochure setting out the *Special Education Policy Guidelines*:

The brochure enclosed with this update is a revised version of the guidelines first published in 1995 by the National Advisory Committee on Special Education. It is an important document as it sets out the overriding principles of special education in New Zealand. It is the umbrella document from which the *Special Education 2000* policy has been developed.

Of particular interest to this paper is the principle of partnership as described in the *Special Education Policy Guidelines*:

4. Partnership between parents and education providers is essential in overcoming barriers to learning.

This principle will be visible in practice when:

- 4.1 information about barriers to learning and the provision of resources is shared between parents and education providers;
- 4.2 full information is provided to learners and parents to enable them to make sound educational choices and to participate fully in the enrolment, assessment, planning and programming, placement and monitoring of the learner's progress;
- 4.3 both education providers and parents share in the responsibility for ensuring maximum benefit from the resource;
- 4.4 parents are able to have placement and other decisions reviewed;
- 4.5 parents may choose to be supported by an advocate in assessment, planning, placement, review and appeal processes;
- 4.6 schools and early childhood services consult with parents of learners with special needs when recruiting and appointing special education staff.

In *Sharpening the Focus Issue 6* (May 2001), Boards of Trustees, principals and teachers are reminded of their responsibilities to meet the requirements of *NAG 1*. The school should be "working in partnership with parents" as they "consider national expectations and then set realistic goals for all students, including those with special needs" (pp. 2-3). At the end of 2001 a collection of 3 booklets on *Meeting Special Education Needs at School* was released. There is a booklet for Boards of Trustees, one for parents, and one for schools. In a two-page summary of *Information to Boards of Trustees*, partnership is again highlighted as fundamental to best practice. The summary states

Quality partnerships between boards, schools, specialists, parents, caregivers and families/whānau will:

- Provide strong platform for meeting special education needs for readily resolving any issues as they arise [sic].
- Promote relationship building.
- Encourage open consultation and communication.
- Model mutual respect and provision of feedback without fear of repercussion.

Fine (1993) and Vincent and Tomlinson (1997) have strongly critiqued this notion of partnership, arguing that the effect is that, rather than resulting in a sharing of power, parents are invited to share the blame for the continued failure of policy and of individual schools to really improve the lives and outcomes of students with disabilities.

Aotearoa New Zealand literature on "partnership"

Debates about the meanings of partnership precede the development and implementation of SE2000. This section summarises some of the literature on parent-professional partnership.

Parent-professional partnership has different meanings for parents than for professionals, and appears to change in different contexts, particularly in the shift from early childhood/early

intervention to primary school. By school age, most discussion seems to focus around partnership in the context of the Individualised Education Plan (IEP) process, with recommendations for a successful IEP process focussing on managing relationships prior to and during IEP meetings. Timperley and Robinson (2002) review literature that is critical of oversimplification “partnership”, confusing it with “participation.”

Fraser (2000) described a number of studies examining partnership, between educators and parents of children with special needs, as well as in the larger educational context. She listed a number of barriers to partnership:

- Lip service – policies espousing partnership are not really put into practice
- Schools as hostile environments – the lay out and practices are not welcoming for parents.
- Teacher assumes the role of expert – which acts to undermine parents’ experiences and knowledge of their child and their child’s needs, skills, etc.
- The student is not respected – neither they, nor their ideas, are valued.
- Parents are directed what to do – rather than a process of discussion and shared decision-making.
- Parents are treated as having a disability – and seen as ‘part of the problem.’
- Teachers are not valued – their commitment and responsibilities may be unknown to parents and/or unrecognised.
- Parents are put in an overload situation – school may be the only break parents have, and they may not wish to have to ‘help out’ at school.
- Family are not included – there may be wider family involvement than just, or even instead of, immediate family.
- Feelings of parents are not understood – a lack of empathy can further isolate parents.

Fraser (2000) describes the *effective teacher*, who recognises and responds to “underlying power dynamics” and so is able to “welcome and include all parents and families” (p.120). The qualities of the effective teacher include:

- Valuing people
- Regarding others as well-intentioned
- Regarding others as a source of satisfaction
- Listening well
- Being sincere
- Being honest
- Being knowledgeable.

These characteristics would ideally imbue all relationships between educators and parents, and not be limited to developing an IEP. The IEP process has been pivotal to considerations of partnerships in New Zealand. Moltzen (2000) wrote about partnership in the context of describing best practices around the IEP process: “without doubt one of the real benefits that has accrued from the IEP process has been the coming together of parents and professionals to share information and collaborate in planning for learners with special need” (p.133). Most children with special needs, those funded through SEG, are no longer required to have an IEP. Moltzen (2000) suggests that the removal of the compulsory element for most children should improve the quality of IEPs, particularly as IEPs are no longer tied to accessing resources. It may also be that the IEP as a vehicle for shared decision-making, and potential partnership, has been removed for most students.

A number of studies in New Zealand report that both educators and parents consider that parental involvement is important to the success of the IEP process (e.g. Moltzen, 2000; Thomson & Rowan, 1995, Wartmann, 1997). Educators and parents differ as to the nature of that involvement.

Previous research (Moltzen & Mitchell, 1992; cited in Moltzen, 2000) showed that while almost all principals and parents agreed that parents should be involved in the IEP process. Nevertheless "some principals viewed the parents' role as a supportive one, and not one central to the decision-making process" (p.135). Moltzen also cited Stringer's (1997) study which described the ways teachers and parents interpret partnerships in the context of IEPs. According to Stringer, teachers see partnerships as

- Collaborative teamwork between parents, teachers and others
- Sharing of expertise for the benefit of the child
- Sharing in the decision-making and sharing responsibility for outcomes
- A degree of commitment from parents and caregivers.

However, while parents reiterated these notions, they added the following points:

- Partnerships should be balanced, with parents empowered to voice their opinions and have these valued, accepted and acted on; and
- There should be clearer communication between professionals and parents so concerns can be addressed quickly and feedback provided (Stringer, 1997; cited in Moltzen, 2000, pp.135-136).

In his summary of the research, Moltzen (2000, p. 136) concludes that parents often report feeling that there is "an imbalance of power in the IEP process" and that parents feel that neither they, nor their views, enjoy status equal to that of the professionals. Lastly, he provided some guidelines for organising and running IEP meetings that aim to ensure that "each member has an opportunity to speak, understands and is understood, valued and respected" (p.141).

Reviewing the literature on parent involvement in, and perceptions of, early intervention, Barwick (1998) summarised a study by Dinnebeil and Rule (1994) that identified the characteristics professionals and parents believed most contributed to collaboration:

...the three characteristics of professionals that parents believed contributed most to collaboration were that they:

- made an effort to build rapport – this involved building positive relationships by disclosing personal information, showing enthusiasm for family accomplishments and using active listening skills
- provided information – providing information about resources, and being prepared to search out particular information parents might want
- demonstrated concern for children – showed they had a 'feeling for children' (not just the child with a disability) or had 'general experience with children', and was confident in relating to them.

Professionals rated the following as the characteristics of those parents who they believed contributed most to collaboration. They:

- demonstrated helpful actions – the consistency with which parents attended visits and followed through on activities
- had good communication skills – were able to articulate their needs and interact assertively with the co-ordinator
- showed a positive attitude – towards their child, the co-ordinator and their abilities as a parent (p. 25).

Barwick (1998) also reported that “Parents need to fight for services and advocate for their child – for some parents it had taken some time to realise the extent to which this is true and for them it would have been helpful to find out sooner” (p.24).

Writing by parents also takes up the theme of having to fight for services. Brown has questioned the stated aims of “partnership” (p.237):

The so-called parent professional partnership has had a rather hollow ring to it for many parents. In reality it has involved a constant challenge to change professional attitudes, often at great personal cost. Progress has been made – but at what price? Repeatedly, parents have to prove their children’s worth; rarely is there wholesale acceptance of them as individuals with their own valued uniqueness. Year after year parents struggle to change attitudes, beliefs, misconceptions. Just as one teacher becomes attuned to a child’s needs, the year closes and the child moves on and more parent energies have to be invested in educating a new teacher, even more so when a shift of school is involved. For many parents, nearly every ‘victory’ has been bitter-sweet, won at great personal cost, and demanding constant vigilance and total advocacy for their child.

Brown described a workshop where parents were asked to list examples of verbal barriers they had experienced in the education system. Many of the parents were assertive, and were also professionals; yet “all of the parents felt they were at the mercy of professionals” (p.238).

Trying to negotiate the quicksands of school and educational policies can be devastating for any parents, especially if an adversarial feeling exists. ... So where does the reluctance to share or compromise arise from? Most parents would say it is because power is firmly stacked in the educational professionals’ favour. Even after the Picot reforms and the finely-stated intentions of greater parents and community involvement, parents still feel they lack power relative to professionals. Also, parents have had to educate some Boards of Trustees on the rights of children with special needs(p.238).

Brown described the barriers to full partnership as “basic issues of power and prejudice” towards children with disabilities, and often towards their parents as well (p.239).

Wills (1994) has also questioned the emerging rhetoric of “partnership”:

In recent times there has been talk of power sharing through ‘parent-professional partnership’. The much vaunted parent-professional partnership runs the risk of becoming little more than a code used by the professionals to describe what they think they should do. How can a partnership exist when inequality of information, financial and material resources are the basis of the relationship? Lifelong needs, wants and hopes drive one of the parties in this relationship. What is the rationale for the involvement of the other? We don’t need a partnership. We would like some of the financial resources, more of the information and all of the decision-making and control (p. 258).

Writing about the origins of parent involvement in and advocacy for their children’s education, Wills (1994) points out that it is not really surprising that parents take on certain roles:

Where others appear to be uncertain, unable or unwilling, it makes sense that parents often become learners or teachers, to support their own children. Encouraged by the active role they have in early intervention for their child, it makes sense for parents to maintain their active involvement and to carry on, keeping up with the issues, the needs, and the latest approaches, in fact doing much of the job of a service provider. In taking this approach, many parents challenge what they perceive as a lack of responsibility by those professionals who fail to keep up with the literature and to implement new ideas, techniques and approaches, and who fail to be strong advocates for children (pp. 259-260).

Dixon (1994) wrote about life with her family of four children, including Jeff who has severe disabilities:

I spend a lot of energy in organising what for most people would seem like very ordinary experiences. I suspect this is true of most caregivers with children who are disabled. You see, that is what we want: ordinary experiences helping to make our children ordinary (pp. 71-72).

Having an ordinary life only comes with extraordinary amounts of planning and work.

Maybe if I list the people currently involved in Jeff's life you will begin to understand the managerial and communication responsibilities I carry and thus the difficulties of organising 'regular' things for us all.

In the school situation [pre SE2000] there are the class teacher, two teacher aides, the principal, psychologist, itinerant teacher for special needs, speech language therapist, advisor for the deaf and occupational therapist. The school is now up to the third principal in the three-year period that Jeff has been there and it feels daunting to have to re-explain a complex situation and develop my relationship yet again with a person in this position (Dixon, 1994, p.75).

This list does not include all of the out-of-school organising that goes on so that Jeff can participate in other ordinary activities. Dixon summarises the hard work and what it might be like if all parents worked this hard to achieve the things they now take for granted:

Apart from being stropky, we need to constantly reassure everyone that they are doing well, talk about our son's development, explain, explain, explain a lot of things that are really nobody else's business.

If being a regular parent involved doing a third of the things parents of children labelled disabled do, then the human race would rapidly become extinct (p.77).

The work of parenting a child with special needs at the very least includes, if it is not in fact dominated by, the work of 'managing' other key adults in the child's life. Parents of children with special needs may arrive at school with at least five years' experiences of "managerial and communication responsibilities." Their expectation, and experience, is that for each teacher they encounter, it will be that teacher's first experience with *their* child, and for most teachers, the first experience with *any* child with disabilities. Parents may have an expectation of active involvement based on their experiences in early intervention; they will probably have had at least some experience of having to advocate for their child.

Evaluation of SE2000

Wylie (2002, p.1) describes the results of her evaluation of the Special Education 2000 policy:

One of its major themes was the fragmentation of responsibilities and provision, which undermined the policy's intentions to improve educational experiences and outcomes for students with special needs.

In a three year evaluation of SE2000, one of the research questions explored the quality of the relationships between schools and families in each of three phases of the evaluation (Bourke et al., 2002). The themes identified and examined included:

- information and communication
- decision-making(including the use of funding) and consultation
- the idea and experience of partnership

Information and communication

One of the factors that contributed to a sense of a good relationship was a feeling that communication was open and information shared. Parents had varying experiences of how easy they found it to get information from schools or (the then) Special Education Services (SES). Some were frustrated with the amount of time it took to get information and others questioned the reliability of the information they received.

Almost half the schools surveyed considered that they could not improve communication with the families, caregivers and whanau of students with special education needs. However, in the parent survey the same year, 64% of parents felt that they were not given enough information, and almost half indicated that schools could improve their communication with parents.

Decision making, funding, and consultation

During Phases One and Two schools reported that SE2000 had made little difference to parent involvement. By Phase Three, however, schools had detected an increased involvement of parents in IEPs and behaviour management plans and attributed this to the special education policy. Between 2000 and 2001 schools were less likely to report that they thought parents expected too much involvement in their child's programme.

Schools continued to be ambivalent about the involvement of parents in decisions about funding allocation. About three-quarters of parents felt they had been able to have a say in their child's programme, but several comments reflected some doubts about whether the consultation gave them real involvement or was simply paying lip-service.

Parents were much more likely than schools to think that they should be involved in decisions about funding. Parents were sometimes suspicious about the equitable allocation of funding, and whether or not actual allocated funding was being spent on their child. Funding, whether satisfactory or contested, was pivotal to the sense of partnership.

Ideas and experiences of partnership

With respect to expectations of involvement, parents were not a homogeneous group. Some were happy to be involved on an 'as-needed' basis, some were unhappy that 'as-needed' happened far too frequently, some were unhappy that they are treated as if they had nothing to offer or were interfering. How much parental involvement is enough? Expectations seemed to be worked out on the run, rather than at the beginning of the relationship between school and home. Literature from the Ministry to date does not suggest how parents and educators might better understand each other's perspectives, or how such new understandings might be applied to better achieve partnership, to make such a partnership work toward the best possible education for all children.

In Phase 2, one parent reported:

I feel I have a normal relationship with the school. But do they see me as problematic? Am I too sensitive? We have no relief teacher's aide for my daughter. So if the teacher's aide is sick, the school asks that my daughter stay home. The school has told me to find someone.

One school reported that:

We've got all nice children this year. The difficult families have left.

Schools and families both struggle when relationships become tense. Murray (2000) writing from a parental perspective argues that

... the relationship between parents of disabled children with learning difficulties and educational professionals is one which is fraught with issues of social conditioning and power. The word partnership has been used and misused within this context to such an extent that it now carries little real meaning (p.695).

Vincent and Tomlinson (1997, p.367) offer a strong critique of the use of 'partnership':

'Partnership' is a term which suggests equals involved in a mutually supportive dialogue. The language of partnership employs phrases suggestive of such a relationship: 'parents are the child's first educator' and 'creating trust and co-operation between home and school', for example (Alexander et al., 1995). However, such a conceptualisation fails to recognise the way in which teachers have, by virtue of their location within an institution and their professional knowledge, a built-in command over the relationship (Phtiaka,

1996; Davies, 1996). Will Cowburn argues that the concept of partnership is simply a device to maintain professional control through the co-option of parental support.

This critique by Vincent and Tomlinson can be seen as a failure of the rationale of partnership as enhancing social democracy. The evaluation of *SE2000* suggests that, by and large, parent participation is most welcomed to the extent that – at worst, it helps to solve the problem of individual disabled students attending school – at best, it helps to solve the problem of individual disabled students achieving at school.

Murray (2000) contends that underpinning the tensions are different views of the meaning of disability.

... until policy, legislation and practice moves from its present perspective of viewing disability as a failure of the individual to that of a perspective of embracing equality of value for all, relationships between parents and professionals will be fraught with difficulties. Furthermore, it is argued that until disabled children are centrally and positively placed within the relationship between parents and professionals, the existing prejudice and oppression experienced by disabled children will dominate the relationship (p.683).

In this last section we turn to the meanings of disability within partnership.

Making a World of Difference: The New Zealand Disability Strategy

This paper is written from a social-political model of disability perspective. This perspective contrasts with how disability has been viewed historically, and still is viewed by much of society: the medical model.

In New Zealand society disability is usually seen as a medical problem, or an extension of a medical problem. The disability community refers to this framework as the “medical model of disability”. This model individualises people’s needs and sees them as requiring treatment.

Without using these particular terms, what the Disability Strategy is arguing for is a socio-political analysis of disability, disability as oppression, disability as a human rights issue. What the Strategy is arguing against are the dominant discourses of disability. These are the dominant discourses that inform our everyday practices as town planners and architects, as educators and teacher trainers, as neighbours, as classmates, as parents. These dominant discourses of disability are the medical discourse, the charity discourse and the lay discourse.

The most pervasive and influential of these is the medical discourse of disability, with its professional and clinical focus on the body. The themes of the medical discourse are defect and deficit – and these are inherent to, located within, the individual – a personal problem, a defining identity. The individual is less, less than normal. The goals of the professional are to fix and cure; the assumption that the goal of the individual is to be fixed. This makes the professional the expert, with great authority to pronounce upon the individual, the client. These roles are seen as the natural state of affairs. When a deficit is unable to be fixed, there is an aura of failure. All problems, including any dissatisfaction with service, are pathologised, seen as problems of the individual and her or his deficit.

The second dominant discourse of disability is the charity discourse. The themes of the charity discourse are dependence and helplessness, the perpetual child who is needy. Moreover, the individual, and their families, should be grateful for whatever it is they receive. The charity discourse is also closely connected to the medical discourse, particularly with its institutional and organisational focus. People with impairments, particularly those that cannot be fixed, remind us too much of our own frailties and mortality – best out of sight, out of mind. Besides, by and large, according to the charity discourse, people with impairments have ‘empty and useless lives’ (Morton & Munford, 1998).

The third discourse is the lay discourse, emerging from the medical and charity discourses. This is our ‘everyday’ knowledge of disability and difference. In the lay discourse, impairments mean that people are inferior, dependent, weak, isolated, to be feared, childlike, asexual (and over-

sexed monsters), to be shunned and rejected. Life with impairment must be awful and not worth living. After all, when someone young and vibrant takes their own life, we say 'they were not in their right mind.' But we can understand why someone who has become impaired might do so. The baddies are always scarred and deviant in the lay discourse (Morris, 1990).

Drawing on a socio-political or rights discourse, the Disability Strategy challenges the dominant discourses of disability. The themes of the rights discourse include inter-dependence, self-determination, and common humanity. The Strategy names disability as discrimination and oppression. That's what we call it when children are excluded from a school on the basis of race, when adults are excluded from a place of work because of gender.

The dominant discourses of disability are the ones that most of us, however unwittingly, draw upon in our daily individual and institutional practices (Corbett, 1996; Morton & Munford, 1998).

In *The Politics Of Disablement* (1990) Oliver drew from the lived experiences of disabled people and how they perceived themselves and their collective identity and sought "to place disability on the political and academic agendas" (Georgeson 1999), paralleling previous rights movements, where concepts of inherent difference were defined and separated from concepts of discrimination. Just as gender and sexism, ethnicity and racism, and more lately sexuality and homophobia separately describe a group's inherent difference, and the specific discrimination imposed on that group by society, Oliver defined impairment in terms of inherent difference; and disability as:

... the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have ... impairments and thus excludes them from the mainstream of social activities (Oliver, 1990:11).

The social model both reinforces the right of citizenship, to be included in the whole community, and the right to collective self-determination, to be a community defining its own direction and need.

The disability community is increasingly using the rhetoric of "inclusion vs. assimilation" to define what partnership is and isn't. Assimilation is about an expectation to fit and to achieve within dominant structures and systems without being given the opportunity to value individual and collective difference. The disability community sees that inclusion implicitly involves elements of self-determination and partnership. People with impairments cannot be assimilated into a disabling society. Our inclusion within will be within a society that is different, and is noticeably more pluralistic, actively seeking partnership as an outcome, not a process to attempt successful assimilation.

The disability community has come to the party later than other of government's partners. Prior to 1999 disability policy was fragmented and visionless. Defining mandate and achieving representation has slowed progress in various government partnerships, and a growing acceptance of the social model of disability has given more clarity to mandate disabled people to lead on disability issues. The hierarchy of voices of service providers first, parents second, and disabled people next had been turned upside down. The disability community was ready to dance, and had a few pick up lines to use. "Nothing about us without us", in reference to the way historically disabled people had been left out of the policy making process, and "who we are is OK, what happens to us is not", a condensed version of the social model.

A change in 1999 to a government committed to a disability strategy, to a social model perspective, and with a Minister working across government departmental boundaries, understanding and committed to disability issues saw a blossoming relationship. The disability community was growing in confidence and assertiveness, and had legitimately high and growing expectations of what could be achieved. Anything seemed possible. In early 2000 the framework was established for the disability strategy, with a reference group, the majority of whom were disabled people. A non-disabled person was chosen by government to chair the group, but the group did not believe this was appropriate, and chose to model partnership through co-chairs, disabled and non-disabled.

The diverse members of the group debated the content of the strategy with a surprising degree of unanimity. The initial gloss started to wear off the relationship with the reference group's understanding of the parameters in which it could work. At the same time other partnerships the government was involved in were going through tough times. The "closing the gaps" programs, addressing socio-economic disparities through action targeting collectives rather than individuals, was under scrutiny, and the basis of using a partnership in this way challenged. Why not target the individual, regardless of group they belong to directly?

There was some confusion about whether the Closing the Gaps programs covered just Maori, or Pacific peoples as well. The Disability reference group put the question to the Minister: Why not call our disability strategy Closing the Gaps because that is exactly what it is about?

The answer was no, to put disability in with the closing the Gaps brand would be seen as compromising those partnerships, being "unfaithful".

A couple of meetings later and a change of Minister, a different question was put. Why not give the strategy some impact? To support the vision, actually quote supporting research, statistics about the size of the various "gaps" between collectives. What little information is available through census analysis suggests disability as a factor has more of an impact on income, educational attainment, community participation, and various other social indicators than gender, being Maori, or being Pacifica, and factors compound in complex ways. There are huge gaps in the social research agenda, both qualitative and quantitative, in building a picture that can positively impact on the allocative efficiency of government, and can help close the gaps. There was no desire by the group to compromise any other strategy or program, but the response from the new Minister, who had only just stepped into the job, was one of surprise at being presented with the "gap: information, and a very strong no to any comparative statistics.

After a draft strategy was written in late 2000, the community beyond the reference group was engaged in consultation. Various communities within the broader disability community were specifically targeted for their own consultation. Consultation itself is a form of research. In many research and consultation projects, general and disability related, meaningful feedback is not received from various communities within the broader disability community because of inaccessible information, be it not in plain language, not in accessible formats, not culturally appropriate, or not interpreted. The consultation was a very genuine attempt to be inclusive, and much was learnt in terms of best practice to be inclusive. The process was to model the outcome.

Again the degree of consensus was very high. The philosophical direction of the draft, the social model, was strongly endorsed. The language used to describe the people at the centre of the strategy was the most contentious issue. Consultees identified the main barrier to their participation in society as other people's attitudes. Expectations were building towards a celebration, a high profile release of the strategy in early 2001.

The final strategy didn't quite live up to expectations for many in the reference group and disability community at the time. It was shorter than the group was expecting, with much being cut. The left-overs were given the name of the Reference group's document. However this would be an exaggeration as much of what the group wanted to include was cut before this stage.

The vision of the strategy is one of partnership as an outcome.

"New Zealand will be inclusive when people with impairments can say they live in:

'A society that highly values our lives and continually enhances our full participation.'

Achieving this vision will involve recognising the principles of the Treaty of Waitangi. Disabled people will have a meaningful partnership with Government, communities and support agencies, based on respect and equality. "

The launch of the strategy was a high profile event in the disability community, but not outside. The Prime Minister launched it, and in the spirit of partnership a disabled person and leader who had not been directly involved in the writing of the strategy, DPA Chief Executive Gary Williams,

gave one of the launch speeches. Gary, of Ngati Porou, looked to the audience of disabled people and said “this is our Treaty”, a partnership in itself, and a means of progressing partnership.

The disability community is more engaged with government now than before the strategy. Government and its agencies are progressively implementing the action points of the strategy and engaging with the disability community to various extents in the process. Partnership to some degree has been an outcome. These are early days yet, and strategies for evaluating the implementation of the Disability Strategy have yet to be detailed – who will have input into posing the questions – including any definitions of the problems that policy should have addressed? What rationales for partnership will be articulated and used as a basis for evaluation?

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